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Lived experience of women with gestational diabetes mellitus living in China: A qualitative interview study

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ABSTRACT

Objectives: To explore the lived experience of women with gestational diabetes mellitus (GDM) living in China in order to add knowledge about how the women suffer from GDM in China where the professional-patient relations are deteriorating.

Design: A qualitative interpretive interview study. Data was collected with a snowball sampling technique. Phenomenological hermeneutics was used as the analysis method based on Ricoeur's phenomenological hermeneutical interpretation theory.

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Setting: The study was performed at the participants' work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China.

Participants: Inclusion criteria were: age ≥ 18 years, diagnosis of gestational diabetes mellitus without other pregnancy complications, in 34th gestational weeks – postpartum 4th weeks, and speaking Mandarin Chinese without speech impediment. 62 women, who met the inclusion criteria, took part in the study.

Results: The lived experience of the women with GDM living in China was formulated into a main theme: 'Longing for caring care'. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring care of GDM; Being left alone to struggle with GDM; and Trying to adjust and adapt to life with GDM.

Conclusion: The eagerness for caring care in China was highlighted. The lack of caring care could be one of the reasons why the professional-patient relations were deteriorating in China. It could be useful for health providers and health policymakers to receive education and training about caring care. Using the health metaphor of balance and 'patient participation' and 'patient-centred' approaches may benefit women with GDM and thus improve the quality of care in China.

Strengths and limitations of this study

- To our knowledge, this is the first study to explore the lived experience of women with GDM living in China where the professional-patient relations are deteriorating.
- The large number of participants (N=62) presented the trustworthiness of the qualitative study.
- By using phenomenological hermeneutics a greater understanding of the essential meaning of living with GDM in the deteriorating professional-patient relations could be attained.

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- We could not free ourselves from our pre-understanding which could produce bias.
- Nuances could be lost in the translation process of the interview texts, which could influence the results of the study.

Introduction

The scale, frequency, and viciousness of violence against health professionals in China have shocked the world.[1] The increasing medical disputes including widely reported violent attacks, murders and protests in hospitals showed the deteriorating relationship between health professionals and patients.[2] As a common disease during pregnancy, gestational diabetes mellitus (GDM) seriously depends on good professional-patient relations in order to obtain satisfied effects of health education due to the strict lifestyle management that women with GDM have to perform.[3] A latest study showed that the prevalence of GDM in China was 8.1% by using the WHO criteria.[4] GDM is becoming a priority issue in public health in China. Therefore, exploring the lived experience of women with GDM living in China would increase the awareness of the essence meaning of living with GDM in the deteriorating professional-patient relations. The awareness often leads to improvements in the healthcare area.

The experiences of women with GDM in some socio-cultural contexts have been reported. In a metasynthesis study including studies from different countries worldwide, women with the illness experienced several negative feelings, such as fear and a loss of normality and personal control,[5] as well as in another study performed in Australia they reported uncertainty and scepticism.[6] Another review study not only revealed women's negative feelings and thoughts, but also explored the women's struggle to manage GDM and their identity changes from a healthy person to being someone with GDM;[7] their adaption to the

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changes; their concern for the health of their babies as well as their own health; their perception of seriousness of GDM and fear of T2DM; and the influencing factors including cultural roles and beliefs, social stigmas, social and professional support, adequate and appropriate information, social roles and barriers to self-care. Furthermore, the experiences of Caucasian and South Asian women with GDM living in Canada illustrated a disconnection between diabetes prevention recommendations and the women's cultural practices.[8] Studies conducted in China showed that the beliefs and health-related behaviour among women with GDM were influenced by Chinese culture and the lack of knowledge.[9,10] Another study conducted in China reported that women perceived a lack of high-quality GDM care.[11] However, to our knowledge, little was known about the lived experience of women with GDM living in China where the professional-patient relations are deteriorating.

In China, pregnant women receive the routine management of GDM[12] including GDM screening, health education, diet control, exercise, self-monitoring blood glucose and urine acetone body, controlling blood pressure, and fetus monitoring. Insulin treatment will be used for the pregnant women whose dietary interventions are unsuccessful in lowering blood glucose. However, the ordinary world could be transcended in the search of the true knowledge by the evidence of our lived experiences,[13] which has become an epistemological foundation for caring science. According to Lindseth and Norberg,[14] in order to be able to understand and improve healthcare practice, we have to start with the lived experience and express it in order to become aware of its meaning. The study thus aimed to explore the lived experience of women with GDM living in China where the professional-patient relations are deteriorating.

Methods

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Design

A qualitative interview study was conducted among women with GDM living in China by using phenomenological hermeneutics[14] inspired by Paul Ricoeur. [15]

Participants and setting

The inclusion criteria of participants were age ≥ 18 years, diagnosis of GDM without other pregnancy complications,[16] in the 34th gestational week – the postpartum 4th week, and speaking Mandarin Chinese without speech impediment. 62 women who met the inclusion criteria took part in the study (Table 1). The median age was 31 years (range 23 - 37). Four women refused to participate in the study, whose reasons were "I don't have time" or "I have to go back home now". The study was performed at the participants' work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China. A single room was chosen for each interview, which was most convenient for the participants. The study was approved by a university ethical board (No. 2012-033), and all conducted procedures conformed to the principles of Declaration of Helsinki.

---INSERT TABLE1 HERE---

Interviews and analysis

Participants were recruited by using a snowball sampling technique.[17] The information about women with GDM was obtained through the recommendation of participants or four midwives who worked at hospital. Women recommended for the study were orally invited to participate in the study. Open-ended questions about the lived experience of women with GDM, which were developed by the authors, were used for data collection (Table 2).

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Individual narrative interviews were conducted face to face during August and December of 2014 by the first author, a native female Chinese with bilingual skills. Each interview lasted between 30~50 minutes, and was recorded with a digital audio recorder, and then transcribed verbatim in Chinese and translated from Chinese to English by the first author. Three pilot interviews were conducted and then discussed among the authors，which were included in this study based on their quality.

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Phenomenological hermeneutics[14] based on Ricoeur's phenomenological hermeneutical interpretation theory [15] was used as the analysis method in this study. The analysis process consisted of three phases: naïve reading, structural analysis, and comprehensive understanding. In the naïve reading, the transcribed interview texts were first merged into one text, and then read several times as open-minded as possible in order to obtain its meaning as a whole. The maintenance of a phenomenological attitude was important during the naïve reading in order to formulate a naïve understanding of the text in phenomenological language.

In structural analysis, the whole text was read and divided into meaning units. The meaning units were read through and reflected on based upon the background of the naïve understanding, and were then condensed and expressed in everyday words as concisely as possible. All the condensed meaning units were read through and reflected on regarding similarities and differences, and then were sorted, further condensed and abstracted to form sub-themes. The sub-themes were reflected on and formulated in such a way as to present what the text talked about, thus leading to the formulation of themes. Reflection about the themes was based on the naïve understanding, and these explored in terms of whether they validated or invalidated the naïve understanding. If the structural analysis invalidated the naïve understanding, the whole text would be read again and a new naïve understanding would be formulated and checked by a new structural analysis. The process was repeated until

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the naïve understanding was indeed validated through the structural analysis.

In the comprehensive understanding, the third analysis phase, the whole text was reread as open-minded as possible with the naïve understanding and the validated themes in mind. Imagination and pre-understanding were used during the process. Relevant literature that seemed appropriate for helping to revise, widen and deepen the understanding were discussed between authors based on the meaning of the lived experience. The literature that could mutually illustrate the interview text was chosen for interpreting the text. The text was kept as close as possible as a whole again and re-contextualized in the light of the literature, and a comprehensive understanding of the text, i.e. the main theme, was attained by focusing on the possibilities of living in the world that the interview text opened up. According to Ricoeur,[15] a text could probably be interpreted in different ways, but the interpretation should be understood dialectically related to each other, overlap and interact with each other. Discussions were performed between authors in order to achieve the dialectical interpretation of the text and the meaning of the lived experience.

Findings

The lived experience of the women with GDM living in China was formulated into a main theme: 'Longing for caring care'. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring GDM care; Being left alone to struggle with GDM; Trying to adjust and adapt to life with GDM.

Naïve analysis

The women in the study described their initial emotional reactions when they were

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informed of the diagnosis of GDM. They experienced shock, doubt, surprise, feeling strange, denial, fear, and worry. They reflected on the reasons of getting it and sought help from the health professionals and popular sectors, i.e. relatives, friends, internet and books. It appears that they did not initially receive the satisfactory answers about GDM from the health professionals, so they sought help from the popular sector. They perceived that the information obtained about GDM was inconsistent. After considering all the information, women were always afraid of and worried about having the illness; or women believed it was not a severe illness; or women thought that it was nothing to worry about. The women's experiences of GDM contained afflictive feelings caused by the illness, helplessness, confusion and neglectful attitude from health professionals and people around.

Structural analysis

Four themes emerged during the structural analysis. These themes were described with sub-themes, condensation units (Table 3), and meaning units.

---INSERT TABLE3 HERE---

Being stricken by GDM

After women in the study were informed of the diagnosis of GDM, they were stricken by emotional chaos. They were shocked and surprised, and felt strange at the beginning. Some of them could not accept the fact, and thus doubted and denied the diagnosis of GDM. Nevertheless, they were afraid of and worried about the negative effects of GDM on their babies and themselves. When the women experienced these emotional reactions, they also reflected on the reasons for getting the illness. They believed the reasons were eating too much fruits and sweets, obesity, and advanced maternal age.

Wishing to receive caring GDM care

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After the women saw the abnormal result of the OGTT, they began to seek help from different resources. A woman said, *"I consulted doctor and some friends who work in hospital... I searched on the internet…. I was a little nervous, so I called my mother".* However, they perceived that the information received about the illness was inconsistent. They thought that the support and encouragement from health professionals and their husbands were important and could promote their health behaviour. They, however, perceived that the GDM care from health professionals was insufficient and lack caring. They complained about the health education from the professionals being unclear and lacking detail because of the large number of patients waiting. Some thought that the doctors and midwives were not professional about GDM and did not take the illness seriously. They wished to receive caring GDM care.

The obstetric doctor just said 'Observation'. I asked 'How do I observe?' She just said 'Come and check OGTT again after a period'…. The doctor still said "Observation" after the second OGTT…. She at most said, 'Pay more attention to your life style, your diet, and your exercise.' I cannot feel they care about me. (Participant 5)

Being left alone to struggle with GDM

After women in the study sought help from different sectors and considered all the information they received, they constructed their personal beliefs about GDM: they believed the illness should be treated seriously, but feel afflictions; or they believed it was not a severe illness, but feel helplessness; or the women believed it was nothing to worry about, but be unawareness. These personal beliefs and experiences showed that women in the study were left alone to struggle with GDM.

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The women who believed GDM should be treated seriously thought that their health was their own, and they should take responsibility for attaining a normal value for their blood glucose level. They were worried about or afraid of the negative effects of GDM, and strove to seek information from health professionals and control GDM. A participant explained her fear of T2DM in the future, which is one of the risks for women with GDM, as well as her notion about the desperate feeling of getting the lifetime disease. "*I'm particularly afraid of getting diabetes in the future…. You may imagine that the disease is getting worse and worse, and in one day you could be like the very sick person that you'd seen."* Some women even systematically searched for GDM knowledge. They fully complied with the advice of health professionals and gave up their previous unhealthy lifestyle and their favourite food, which could increase their blood glucose. They attained the stable normal value of blood glucose, but they felt afflictive because of being restricted from enjoying food, the special way other people looked at, and the pain caused by the needle pricks when self-monitoring blood glucose. A woman talked about their inner struggle about diet control, "*I can't see other people eating, so I have to go away if I see it. But I will still think about the food after I go away, and then come back to have a look…*"

The women who believed GDM was not a severe illness was affected by the views of "*GDM does not matter*" from the health professionals and people around. In terms of behaviour, the women with the style of belief controlled GDM based on the information they received. However, some of them felt helpless because the value of their blood glucose could not be kept in the normal range. Once the value of their blood glucose was normal, the women thought that they recovered from GDM and returned to their previous customary lifestyle. A participant with this thought talked about her confusing and stressful experience after being admitted to hospital.

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I returned to my previous diet. I thought I recovered… I didn't eat breakfast until lunch time. I ate a hamburger and fried chicken. When I woke up the next morning, I felt severely dizzy, and then vomited. I was found the urine acetone bodies after a blood test at hospital…. My blood glucose suddenly increased a lot…. I was admitted to hospital at once. ... I was very worried and surprised…. When I was staying at the hospital, I knew that one woman with the same problem as me arrived at hospital half an hour later, and her baby died in her stomach. (Participant 10)

The women who believed GDM was nothing to worry about almost ignored GDM and didn't know about the future risk of GDM. They thought that their GDM was nothing to worry about because the value of their blood glucose was only a little high; they had seen that the babies born by mothers with GDM were healthy; and their physical body did not have abnormal symptoms. Some women even thought that GDM was not a disease at all. The women thought that they were influenced by the ignoring attitude of health professionals and people around. A participant described the talking situation with her doctor about GDM, "*When the doctor showed me the test report, she didn't tell me that I got diabetes. She only said that the value was a little high. So I didn't pay attention to it.*" The women said that they asked different people after they were diagnosed with GDM. All the people around them said that there was nothing to worry about if the value of the blood glucose was just a little high; and the elderly always said that a big baby was good and very easy to bring up. In terms of behaviour, they almost did nothing related to GDM.

Trying to adjust and adapt to life with GDM

The women in the study had been trying to adjust and adapt to their lives with GDM during their pregnancy. With their foetus growing, they adapted to being a mother with GDM and

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gradually began to enjoy the feeling of being a mother. They believed that their emotions would influence their baby's personality and the health of their babies and themselves. They and their baby would be in a good situation if they were in a good mood. They thus tried to be happy. They also sought a balance between trying to practice a healthy life style and avoiding practical difficulties. For example, they compromised with their parents' views on their life style because they wanted to show filial piety to their parents and parents-in-law by obeying the latter' views even if they did not like their parents' old fashion. Moreover, they continuously reflected on GDM. The women realized that the illness was like an alarm bell for their future health, and reflected a great deal on the effects of GDM on their future health and the current health education of it as well. They believed that people in general were not aware of what GDM was. They thought that the illness should be prevented at the beginning of a pregnancy and that the knowledge about GDM should be disseminated to everyone in society.

Comprehensive understanding

The women with GDM in the study seemed to be suffering due to their illness, treatment and lack of caring care. They complained about the ignoring attitude among health professionals, as well as a lack of health education about GDM and an understanding of GDM from the whole society. It seemed that they were eager to receive professional care and be left alone to struggle with GDM. A study showed that good care from the patients' perspectives were patient-focused, individualized and involved care related to their needs; it was provided in a humanitarian way by the health providers who presented their involvement, commitment and concern to patients.[18] Martinsen points out that caring includes having consideration for, being concerned about, and taking care of the other.[19] According to Eriksson,[20]

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caring, as an ethos of love and compassion, implies alleviation of suffering in love, charity, faith, and hope, and serves life and health. Based on the literature, our comprehensive understanding of the women's narratives was formulated as 'Longing for caring care'.

Discussion

The Chinese women experienced being stricken by emotional chaos after they were diagnosed with GDM. When seeking care, they wished to receive caring GDM care. When they struggled with GDM, they beliefs and experiences showed that they were left alone. However, they tried to adjust and adapt to life with GDM. Their lived experience showed that they longed for caring care.

The women in the present study experienced emotional chaos such as doubt and fear. Similar emotional reactions were showed in a metasynthesis study about perceptions among women with GDM.[5] A study conducted in Canada showed that the strict regime such as diet control increased the women's anxiety and stress during pregnancy.[21] These studies illustrated that women's experiences of living with GDM could be overwhelming. Moreover, women who believed that GDM should be treated seriously strove to control the illness and attained the stable normal blood glucose level, which was similar to the findings in a study.[22] However, they felt afflictive with the strict GDM regime. They did not receive psychological supports from health professionals and people around. They were left alone to face to the afflictions. A study has showed that the psychological aspect was pivotal in helping and encouraging women with GDM to promote self-management of the illness and better control of it.[23] It is suggested that health providers and the women's family members needed to have an understanding and care on the women's psychological wellbeing and on-going mental health.

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Meanwhile, some women in the present study believed that GDM was not a severe illness or that GDM was nothing to worry about, but they felt helplessness or unawareness. One of the reasons for this was the women's perception of GDM: they did not perceive that they had any symptoms; they and their babies were "normal" after being checked in hospital; and they had seen other women with GDM and these women's neonates did not have any problems generated by GDM. A study showed that a lower level of risk awareness about GDM was related to limited knowledge about the body and GDM.[22] Another study showed that lower levels of health literacy and risk awareness of GDM might relate to a risk for poorer self-management of GDM.[24] The present study showed that these women's poorer self-management of GDM related to a lack of necessary knowledge about GDM. For example, one of their misunderstandings on diet control was that they returned to their previous diet once the value of their blood glucose was normal. Another aspect of the reasons for having the beliefs was due to the influence of the ignoring attitude of health professionals and people around. The women in the study complained that they lacked sufficient health education about GDM. They were left alone by health professionals and people around. According to Helman,[25] people suffering from physical discomfort or emotional stress seek help from professional, popular and folk sectors, and thus form their own beliefs and behaviour. They construct their reality of health and illness in aspects of biological and mental patterns, characteristics of their image of body, mind, and soul, ethnicity and family structures of community and society, and experiences of care. The present study showed that women's beliefs were influenced by health professionals and people around them. Orem stated that nursing systems are action systems formed by health providers through the practice of their nursing agency for persons with health-derived or health-associated limitations in self-care or dependent care.[26] The nursing systems may be produced for individuals, for persons who constitute a dependent-care unit, and for families and other multiperson units. Therefore, in

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order to support the women and promote the women's health-related behaviour in the healthcare system, the ignoring attitude of some of health providers ought to be changed; health education about GDM should involve women with GDM, their family members, communities, and society.

Moreover, women in the present study tried to adjust and adapt to life with GDM. They adapted gradually to being a mother with GDM, tried to keep a balance in life, and reflected continuously on GDM. A study in a group of Cambodian women showed that the core perception of health was "seeking life balance".[27] Physical, emotional, spiritual, psychological, and social considerations play different roles in the need for balance. According to Roy,[28] health is a reflection of adaptation, i.e. the interaction of the person and the environment aimed to be a state and a process of being and becoming integrated and a whole human being. In the present study, women presented the process of adjusting and adapting to life with GDM to attain the physiological, psychological, and social integrity. Using the health metaphor concerning balance may thus be better for the health education of women with GDM than the more conventional methods of control and restriction. Making health providers understand patients' needs and thus help patients to reach a life balance, using 'patient participation' and 'patient-centred' approaches may benefit the women with GDM.

Based on the lived experience, the women in the present study seemed to be suffering due to their illness, treatment and lack of caring care. The feeling of caring is generated by the resonance between patients and caregivers, and the acknowledgement of the individual with respect from a person-centred perspective.[29] A study showed that good care from the patients' perspectives were patient-focused, individualized and involved care related to their needs; nor, conversely, care was described as 'Not so good', which was given in an impersonal manner, routine-based, unrelated to needs, and by staff who were distant and did

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not know or were not involved with the patients.[18] According to Eriksson,[20] patients' experiences of suffering related to care are: not to be taken seriously, not to be welcome, being blamed, and being subjected to exercise of power. The present study presented the suffering related to care and reflected on women's eagerness to caring care. It is thus necessary, in professional context, to strengthen caring care for women with GDM in China. Caring, however, requires education and training[19] and thus in order to update and perform the diabetes guidelines and routines with a humanistic care approach, it would be beneficial if health providers and health policymakers received education and training about caring care.

Strengths and limitations

To our knowledge, this is the first study to explore the lived experience of women with GDM living in China where the professional-patient relations are deteriorating. However, the essence of people's lived experiences is what is invariable in all the variations of the phenomenon and is not easily expressed by people.[13] By using phenomenological hermeneutics a greater understanding of the essential meaning of living with GDM in China can be attained,[14] which is possible to make stakeholders related to an illness understand each other better. Moreover, the large number of participants (N=62) who respectively performed antenatal care in five different hospitals also presented the trustworthiness of the qualitative study.

However, we cannot be free ourselves from our pre-understanding, which could produce bias.[30] Through critical reflection, discussion between authors and using relevant literature, we revised, broadened and deepened our awareness, and reduced the bias from our pre-understanding. Meanwhile, losing nuances in the translation process of the interview texts could be another limitation of the study.[31] In order to reduce the translation problems, the first author, who had bilingual skills and have accepted the training of qualitative research

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methodology, transcribed the interviews verbatim in Chinese and translated the texts into English.

Conclusions

The eagerness for caring care in China was highlighted in the study. The lack of caring care could be one of the reasons why the professional-patient relations in China were deteriorating. It could be necessary to strengthen caring care in China by carrying out and updating diabetes guidelines and routines with aspects of humanistic and psychological care, and training health providers and health policymakers in caring care. Using the health metaphor concerning balance and 'patient participation' and 'patient-centred' approaches may benefit the women with GDM and thus improve the quality of GDM care.

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Conflict of interest None declared.

Ethical approval Ethical approval was obtained from the Ethical Committee of Fujian University of Traditional Chinese Medicine, China.

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No	Item	Guide questions/description	Check box
!	"	# $	
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD	
3.	Occupation	What was their occupation at the time of the study?	
4.	Gender	Was the researcher male or female?	
5.	Experience and training	What experience or training did the researcher have?	
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	X
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
8.	Interviewer characteristics	What characteristics were reported about the interviewer /facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
!	$		
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
10.	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
11.	Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	
12.	Sample size	How many participants were in the study?	
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	
Setting			
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	
16.	Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	

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Addendum

20. Field notes	Were field notes made during and/or after the interview or focus group?	X
21. Duration	What was the duration of the interviews or focus group?	
22. Data saturation	Was data saturation discussed?	X
23. Transcripts returned	Were transcripts returned to participants for comment and /or correction?	X
! $ %		
Data analysis		
24. Number of data coders	How many data coders coded the data?	
25. Description of the coding tree	Did authors provide a description of the coding tree?	X
26. Derivation of themes	Were themes identified in advance or derived from the data?	
27. Software	What software, if applicable, was used to manage the data?	X
28. Participant checking	Did participants provide feedback on the findings?	X
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	
30. Data and findings consistent	Was there consistency between the data presented and the findings?	
31. Clarity of major themes	Were major themes clearly presented in the findings?	
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

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Lived experience of women with gestational diabetes mellitus living in China: A qualitative interview study

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% & Gestational diabetes; Qualitative Research; Life experiences; China

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-+.) .

/ 0 To explore the lived experience of women with gestational diabetes mellitus (GDM) living in China in order to add knowledge about how the Chinese women suffer from GDM.

" A qualitative interpretive interview study. Data was collected with a snowball sampling technique. Phenomenological hermeneutics was used as the analysis method based on Ricoeur's phenomenological hermeneutical interpretation theory.

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+ The study was performed at the participants' work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China.

! Inclusion criteria were: age ≥ 18 years, diagnosis of gestational diabetes mellitus without other pregnancy complications, in 34th gestational weeks – postpartum 4th weeks, and speaking Mandarin Chinese without speech impediment. 62 women, who met the inclusion criteria, took part in the study.

) The lived experience of the women with GDM living in China was formulated into a main theme: 'Longing for caring care'. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring care of GDM; Being left alone to struggle with GDM; and Trying to adjust and adapt to life with GDM.

The eagerness for caring care in China was highlighted. The lack of caring care could be one of the possible reasons why the professional-patient relations were deteriorating in China. It could be useful for health providers and health policymakers to receive education and training about caring care. Using the health metaphor of balance and 'patient participation' and 'patient-centred' approaches may benefit women with GDM and thus improve the quality of care in China.

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- To our knowledge, this is the first study to explore the lived experience of women with GDM living in China.
- The large number of participants (N=62) presented the trustworthiness of the qualitative study.
- By using phenomenological hermeneutics a greater understanding of the essential meaning of living with GDM in China could be attained.
- We could not free ourselves from our pre-understanding which could produce bias.

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- Nuances could be lost in the translation process of the interview texts, which could influence the results of the study.

1

Diabetes is a major health problem in China where the highest number of deaths in the world due to the illness has been recorded [1]. One of the types of diabetes, gestational diabetes mellitus (GDM) is associated with type 2 diabetes mellitus (T2DM); women who have been previously diagnosed with GDM will run a greater risk of developing T2DM later in life and GDM in subsequent pregnancies [2]. GDM plays a crucial role in the increasing prevalence of diabetes and obesity [3]. Uncontrolled GDM is also associated with serious complications for women with the illness and their foetus, for instance, obstructed labour and congenital abnormalities [3]. According to a study in 2015 in Tianjin of China, the prevalence of GDM in China is 8.1% by using the WHO criteria [4]. GDM is becoming a priority issue in public health of China. A recent study conducted in China reported that women living with GDM perceived a lack of high-quality GDM care.[5] According to Lindseth and Norberg [6], in order to be able to understand and improve healthcare practice, we have to start with the lived experience and express it in order to become aware of its meaning. This awareness itself often leads to improvements in the healthcare field.

The experiences of women with GDM in some socio-cultural contexts have been reported. In a metasynthesis study including studies from different countries worldwide, women with the illness experienced several negative feelings, such as fear and a loss of normality and personal control,[7] as well as in another study performed in Australia they reported uncertainty and scepticism.[8] Another review study[9] not only revealed women's negative feelings and thoughts, but also explored the women's struggle to manage GDM and their

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identity changes from a healthy person to being someone with GDM; their adaption to the changes; their concern for the health of their babies as well as their own health; their perception of seriousness of GDM and fear of T2DM. Furthermore, the experiences of Caucasian and South Asian women with GDM living in Canada illustrated a disconnection between diabetes prevention recommendations and the women's cultural practices.[10] However, to our knowledge, little was known about the lived experience of women with GDM living in China.

Studies conducted in China showed that the beliefs and health-related behaviour among women with GDM living in China were influenced by Chinese social culture.[11,12] A review study revealed that the influencing factors of the experience of women living with GDM included cultural roles and beliefs, social stigmas, social and professional support, and social roles and barriers to self-care.[9] In China, the social context is that the scale, frequency, and viciousness of violence against health professionals have shocked the world.[13] The increasing medical disputes including widely reported violent attacks, murders and protests in hospitals showed the deteriorating relationship between health professionals and patients.[14] However, GDM seriously depends on good professional-patient relations in order to obtain satisfied effects of health education due to the strict routine and lifestyle management that women with GDM have to perform.[15] Therefore, exploring the lived experience of women with GDM living in China would add knowledge of what it is like to live with GDM and how suffer it is for Chinese women. The study thus aimed to explore the lived experience of women with GDM living in China.

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Design

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A qualitative interview study was conducted among women with GDM living in China by using phenomenological hermeneutics[6] inspired by Paul Ricoeur. [16]

Participants and setting

The inclusion criteria of participants were age ≥ 18 years, diagnosis of GDM without other pregnancy complications,[17] in the 34th gestational week – the postpartum 4th week, and speaking Mandarin Chinese without speech impediment. 62 women who met the inclusion criteria took part in the study (Table 1). The median age was 31 years (range 23 - 37). Four women refused to participate in the study, whose reasons were “I don’t have time” or “I have to go back home now”. The study was performed at the participants’ work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China. A single room was chosen for each interview, which was most convenient for the participants. The study was approved by a university ethical board (No. 2012-033), and all conducted procedures conformed to the principles of Declaration of Helsinki.

---INSERT TABLE1 HERE---

Interviews and analysis

Participants were recruited by using a snowball sampling technique.[18] Women with GDM were referred to the interviewee of the study by participants or by four midwives who worked at hospital, and were then orally invited to participate in the study. They were first informed of the aim and the procedures of the study, and were assured of the right to withdraw at any time without negative consequences. They were informed that all transcripts were anonymous, and the analysis of data and presentation of results were carried out in such

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a way that no individual could be identified. They took part in the study voluntarily and their written informed consent was obtained.

Open-ended questions about the lived experience of women with GDM, which were developed by the authors, were used for data collection (Table 2). Individual narrative interviews were conducted face to face during August and December of 2014 by the first author, a native female Chinese with bilingual skills. Each interview lasted between 30~50 minutes, and was recorded with a digital audio recorder, and then transcribed verbatim in Chinese and translated from Chinese to English by the first author. Three pilot interviews were conducted and then discussed among the authors，which were included in this study based on their quality.

---INSERT TABLE2 HERE---

Phenomenological hermeneutics[6] based on Ricoeur's phenomenological hermeneutical interpretation theory [16] was used as the analysis method in this study. The analysis process consisted of three phases: naïve reading, structural analysis, and comprehensive understanding. In the naïve reading, the transcribed interview texts were first merged into one text, and then read several times as open-minded as possible in order to obtain its meaning as a whole. The maintenance of a phenomenological attitude was important during the naïve reading in order to formulate a naïve understanding of the text in phenomenological language.

In structural analysis, the whole text was read and divided into meaning units. The meaning units were read through and reflected on based upon the background of the naïve understanding, and were then condensed and expressed in everyday words as concisely as possible. All the condensed meaning units were read through and reflected on regarding similarities and differences, and then were sorted, further condensed and abstracted to form sub-themes. The sub-themes were reflected on and formulated in such a way as to present what the text talked about, thus leading to the formulation of themes. Reflection about the

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themes was based on the naïve understanding, and these explored in terms of whether they validated or invalidated the naïve understanding. If the structural analysis invalidated the naïve understanding, the whole text would be read again and a new naïve understanding would be formulated and checked by a new structural analysis. The process was repeated until the naïve understanding was indeed validated through the structural analysis.

In the comprehensive understanding, the third analysis phase, the whole text was reread as open-minded as possible with the naïve understanding and the validated themes in mind. Imagination and pre-understanding were used during the process. Relevant literature that seemed appropriate for helping to revise, widen and deepen the understanding was discussed between authors based on the meaning of the lived experience. The literature that could mutually illustrate the interview text was chosen for interpreting the text. The text was kept as close as possible as a whole again and re-contextualized in the light of the literature, and a comprehensive understanding of the text, i.e. the main theme, was attained by focusing on the possibilities of living in the world that the interview text opened up. According to Ricoeur,[16] a text could probably be interpreted in different ways, but the interpretation should be understood dialectically related to each other, overlap and interact with each other. Dialectical interpretation of the text and the meaning of the lived experience were achieved by discussion between the three authors.

2

The lived experience of the women with GDM living in China was formulated into a main theme: ‘Longing for caring care’. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring GDM care; Being left alone to struggle with GDM; Trying to adjust and adapt to life with GDM.

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Naïve analysis

The women in the study described their initial emotional reactions when they were informed of the diagnosis of GDM. They experienced shock, doubt, surprise, feeling strange, denial, fear, and worry. They reflected on the reasons of getting it and sought help from the health professionals and popular sectors, i.e. relatives, friends, internet and books. It appears that they did not initially receive the satisfactory answers about GDM from the health professionals, so they sought help from the popular sector. They perceived that the information obtained about GDM was inconsistent. After considering all the information, women were always afraid of and worried about having the illness; or women believed it was not a severe illness; or women thought that it was nothing to worry about. The women's experiences of GDM contained distressed feelings caused by the illness, helplessness, confusion and neglectful attitude from health professionals and people around.

Structural analysis

Four themes emerged during the structural analysis including being stricken by GDM, wishing to receive caring GDM care, being left alone to struggle with GDM, trying to adjust and adapt to life with GDM. These themes were described with sub-themes, condensation units, and meaning units.

Being stricken by GDM (Table 3)

After women in the study were informed of the diagnosis of GDM, they were stricken by emotional chaos. They were shocked and surprised, and felt strange at the beginning. Some of them could not accept the fact, and thus doubted and denied the diagnosis of GDM.

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Nevertheless, they were afraid of and worried about the negative effects of GDM on their babies and themselves. When the women experienced these emotional reactions, they also reflected on the reasons for getting the illness. They believed the reasons were eating too much fruits and sweets, obesity, and advanced maternal age.

---INSERT TABLE3 HERE---

Wishing to receive caring GDM care (Table 4)

After the women saw the abnormal result of the OGTT, they began to seek help from different resources. A woman said, *"I consulted doctor and some friends who work in hospital... I searched on the internet…. I was a little nervous, so I called my mother".* However, they perceived that the information received about the illness was inconsistent. They thought that the support and encouragement from health professionals and their husbands were important and could promote their health behaviour. They, however, perceived that the GDM care from health professionals was insufficient and uncaring. They complained about the health education from the professionals being unclear and lacking detail because of the large number of patients waiting. Some thought that the doctors and midwives were not professional about GDM and did not take the illness seriously. They wished to receive caring GDM care.

The obstetric doctor just said 'Observation'. I asked 'How do I observe?' She just said 'Come and check OGTT again after a period'…. The doctor still said "Observation" after the second OGTT…. She at most said, 'Pay more attention to your life style, your diet, and your exercise.' I cannot feel they care about me. (Participant 5)

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Being left alone to struggle with GDM (Table 5)

The beliefs and experiences of the women in the study could be divided into three styles: they believed the illness should be treated seriously, but feel afflictions; or they believed it was not a severe illness, but feel helplessness; or they believed it was nothing to worry about, but be unawareness. These personal beliefs and experiences showed that women in the study were left alone to struggle with GDM.

The women who believed GDM should be treated seriously thought that their health was their own, and they should take responsibility for attaining a normal value for their blood glucose level. They were worried about or afraid of the negative effects of GDM, and strove to seek information from health professionals and control GDM. A participant explained her fear of T2DM in the future, which is one of the risks for women with GDM, as well as her notion about the desperate feeling of getting the lifetime disease. "*I'm particularly afraid of getting diabetes in the future…. You may imagine that the disease is getting worse and worse, and in one day you could be like the very sick person that you'd seen."* Some women even systematically searched for GDM knowledge. They fully complied with the advice of health professionals and gave up their previous unhealthy lifestyle and their favourite food, which could increase their blood glucose. They attained the stable normal value of blood glucose, but they felt distressed because of being restricted from enjoying food, the special way other people looked at, and the pain caused by the needle pricks when self-monitoring blood glucose. A woman talked about their inner struggle about diet control, "*I can't see other people eating, so I have to go away if I see it. But I will still think about the food after I go away, and then come back to have a look…*"

The women who believed GDM was not a severe illness were affected by the views of "*GDM does not matter*" from the health professionals and people around them. In terms of

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behaviour, the women with the style of belief controlled GDM based on the information they received. However, some of them felt helpless because the value of their blood glucose could not be kept in the normal range. Once the value of their blood glucose was normal, the women thought that they recovered from GDM and returned to their previous customary lifestyle. A participant with this thought talked about her confusing and stressful experience after being admitted to hospital.

I returned to my previous diet. I thought I recovered… I didn't eat breakfast until lunch time. I ate a hamburger and fried chicken. When I woke up the next morning, I felt severely dizzy, and then vomited. I was found the urine acetone bodies after a blood test at hospital…. My blood glucose suddenly increased a lot…. I was admitted to hospital at once. ... I was very worried and surprised…. When I was staying at the hospital, I knew that one woman with the same problem as me arrived at hospital half an hour later, and her baby died in her stomach. (Participant 10)

The women who believed GDM was nothing to worry about almost ignored GDM and did not know about the future risk of GDM. They thought that their GDM was nothing to worry about because the value of their blood glucose was only a little high; they had seen that the babies born by mothers with GDM were healthy; and their physical body did not have abnormal symptoms. Some women even thought that GDM was not a disease at all. The women thought that they were influenced by the ignoring attitude of health professionals and people around them. A participant described the talking situation with her doctor about GDM, "*When the doctor showed me the test report, she didn't tell me that I got gestational diabetes. She only said that the value was a little high. So I didn't pay attention to it.*" The women said that they asked different people after they were diagnosed with GDM. All the people around

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them said that there was nothing to worry about if the value of the blood glucose was just a little high; and the elderly always said that a big baby was good and very easy to bring up. In terms of behaviour, they almost did nothing related to GDM.

---INSERT TABLE5 HERE---

Trying to adjust and adapt to life with GDM (Table 6)

The women in the study had been trying to adjust and adapt to their lives with GDM during their pregnancy. With their foetus growing, they adapted to being a mother with GDM and gradually began to enjoy the feeling of being a mother. They believed that their emotions would influence their baby's personality and the health of their babies and themselves. They and their baby would be in a good situation if they were in a good mood. They thus tried to be happy. They also sought a balance between trying to practice a healthy life style and avoiding practical difficulties. For example, they compromised with their parents' views on their life style because they wanted to show filial piety to their parents and parents-in-law by obeying the latter' views even if they did not like their parents' old fashioned views. Moreover, they continuously reflected on GDM. The women realized that the illness was like an alarm bell for their future health, and reflected a great deal on the effects of GDM on their future health and the current health education of it as well. They believed that people in general were not aware of what GDM was. They thought that the illness should be prevented at the beginning of a pregnancy and that the knowledge about GDM should be disseminated to everyone in society.

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Comprehensive understanding

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The women with GDM in the study seemed to be suffering due to their illness, treatment and lack of caring care. They complained about the neglectful attitude to GDM among health professionals, as well as a lack of health education about GDM and an understanding of GDM from the whole society. It seemed that they were eager to receive professional care and not be left alone to struggle with GDM. A study showed that good care from the patients' perspectives was patient-focused, individualized and involved care related to their needs; it was provided in a humanitarian way by the health providers who presented their involvement, commitment and concern to patients.[19] Martinsen points out that caring includes having consideration for, being concerned about, and taking care of the other.[20] According to Eriksson,[21] caring, as an ethos of love and compassion, implies alleviation of suffering in love, charity, faith, and hope, and serves life and health. Based on the literature, our comprehensive understanding of the women's narratives was formulated as 'Longing for caring care'.

"

The Chinese women experienced being stricken by emotional chaos after they were diagnosed with GDM. When seeking care, they wished to receive caring GDM care. When they struggled with GDM, their beliefs and experiences showed that they were left alone. However, they tried to adjust and adapt to life with GDM. Their lived experience showed that they longed for caring care.

The women in the present study experienced emotional chaos such as doubt and fear. Similar emotional reactions were showed in a metasynthesis study about perceptions among women with GDM.[7] A study conducted in Canada showed that the strict regime such as diet control increased the women's anxiety and stress during pregnancy.[22] These studies

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illustrated that women's experiences of living with GDM could be overwhelming. Moreover, women who believed that GDM should be treated seriously strove to control the illness and attained a stable normal blood glucose level, which was similar to other study findings.[23] However, they felt distressed with the strict GDM regime. Some women felt unsupported by health professionals and their own close contacts/family on the GDM regime. They were left alone to face to the distress. A study has showed that the psychological aspect was pivotal in helping and encouraging women with GDM to promote self-management of the illness and better control of it.[24] It is suggested that health providers and the women's family members needed to have an understanding and care of the women's psychological wellbeing and on-going mental health.

Meanwhile, some women in the present study believed that GDM was not a severe illness or that GDM was nothing to worry about, but they felt helplessness or unawareness. One of the reasons for this was the women's perception of GDM: they did not perceive that they had any symptoms; they and their babies were "normal" after being checked in hospital; and they had seen other women with GDM and these women's neonates did not have any problems generated by GDM. A study showed that a lower level of risk awareness about GDM was related to limited knowledge about the body and GDM.[23] Another study showed that lower levels of health literacy and risk awareness of GDM might relate to a risk for poorer self-management of GDM.[25] The present study showed that these women's poorer self-management of GDM related to a lack of necessary knowledge about GDM. For example, one of their misunderstandings on diet control was that they returned to their previous diet once the value of their blood glucose was normal. Another aspect of the reasons for having the beliefs was due to the influence of the neglectful attitude to GDM of health professionals and people around. The women in the study complained that they lacked sufficient health education about GDM. They were left alone by health professionals and people around them.

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According to Helman,[26] people suffering from physical discomfort or emotional stress seek help from professional, popular and folk sectors, and thus form their own beliefs and behaviour. They construct their reality of health and illness in aspects of biological and mental patterns, characteristics of their image of body, mind, and soul, ethnicity and family structures of community and society, and experiences of care. The present study showed that women's beliefs were influenced by health professionals and people around them. Orem stated that nursing systems are action systems formed by health providers through the practice of their nursing agency for persons with health-derived or health-associated limitations in self-care or dependent care.[27] The nursing systems may be produced for individuals, for persons who constitute a dependent-care unit, and for families and other multiperson units. Therefore, in order to support the women and promote the women's health-related behaviour in the healthcare system, the neglectful attitude to GDM of some of health providers ought to be changed; health education about GDM should involve women with GDM, their family members, communities, and society.

Moreover, women in the present study tried to adjust and adapt to life with GDM. They adapted gradually to being a mother with GDM, tried to keep a balance in life, and reflected continuously on GDM. A study in a group of Cambodian women showed that the core perception of health was "seeking life balance".[28] Physical, emotional, spiritual, psychological, and social considerations play different roles in the need for balance. According to Roy,[29] health is a reflection of adaptation, i.e. the interaction of the person and the environment aimed to be a state and a process of being and becoming integrated and a whole human being. In the present study, women presented the process of adjusting and adapting to life with GDM to attain the physiological, psychological, and social integrity. Using the health metaphor concerning balance may thus be better for the health education of women with GDM than the more conventional methods of control and restriction. Making

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health providers understand patients' needs and thus help patients to reach a life balance, using 'patient participation' and 'patient-centred' approaches may benefit the women with GDM.

Based on the lived experience, the women in the present study seemed to be suffering due to their illness, treatment and lack of caring care. The feeling of caring is generated by the resonance between patients and caregivers, and the acknowledgement of the individual with respect from a person-centred perspective.[30] A study showed that good care from the patients' perspectives were patient-focused, individualized and involved care related to their needs; nor, conversely, care was described as 'Not so good', which was given in an impersonal manner, routine-based, unrelated to needs, and by staff who were distant and did not know or were not involved with the patients.[19] According to Eriksson,[21] patients' experiences of suffering related to care are: not to be taken seriously, not to be welcome, being blamed, and being subjected to exercise of power. The present study presented the suffering related to care and reflected on women's eagerness to caring care. The lack of caring care in the study could be a possible explanation why the professional-patient relations are declining in China. It is thus necessary, in professional context, to strengthen caring care for women with GDM in China. Caring, however, requires education and training[20] and thus in order to update and perform the diabetes guidelines and routines with a humanistic care approach, it would be beneficial if health providers and health policymakers received education and training about caring care.

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To our knowledge, this is the first study to explore the lived experience of women with GDM living in China. However, the essence of people's lived experiences is what is invariable in all the variations of the phenomenon and is not easily expressed by people.[31]

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By using phenomenological hermeneutics[6] a greater understanding of the essential meaning of living with GDM in China can be attained, which is possible to make stakeholders related to an illness understand each other better and thus improve healthcare practice. The ordinary world of women living with GDM could thus be transcended in the search of the true knowledge by the evidence of their lived experiences.[31] Moreover, the large number of participants (N=62) also presented the trustworthiness of the qualitative study.

However, we cannot be free ourselves from our pre-understanding, which could produce bias.[32] Through critical reflection, discussion between authors and using relevant literature, we revised, broadened and deepened our awareness, and reduced the bias from our pre-understanding. Meanwhile, losing nuances in the translation process of the interview texts could be another limitation of the study.[33] In order to reduce the translation problems, the first author, who had bilingual skills and have accepted the training of qualitative research methodology, transcribed the interviews verbatim in Chinese and translated the texts into English.

The eagerness for caring care in China was highlighted in the study. The lack of caring care could be one of the possible reasons why the professional-patient relations in China were deteriorating. It could be necessary to strengthen caring care in China by carrying out and updating diabetes guidelines and routines with aspects of humanistic and psychological care, and training health providers and health policymakers in caring care. Using the health metaphor concerning balance and ‘patient participation’ and ‘patient-centred’ approaches may benefit the women with GDM and thus improve the quality of GDM care.

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' I would like to express my sincere appreciation to all the women who took part in the study. I thank the healthcare staff for assistance in recruiting participants. I am grateful to Professor David Brunt for revising the manuscript.

Study design was by LG, KW and MR; data collection was by LG; data analysis was by LG, KW and MR; manuscript preparation was by LG, KW and MR; and final approval of the version to be submitted was by LG, KW and MR.

None declared.

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524 . Characteristics of the interviewed Chinese women with GDM (n=62)

Variable	Median (range)	Number
# $	31 (23-37)	62
45 ' 6		39
! ' 6 5 '		23
) ",		5
", '		9
! ",		
No treatment		3
Diet		22
Diet+exercise		29
Diet+Insulin		8
		55
*		44
!		18
3 # $		
Senior Secondary Education (12-13 years)		30
Higher Education (≥ 15 years)		32
! '		
Employed		30
Unemployed		25
Sick-leave		7
2		
Married		61
1		
Obstetric clinic		29
Obstetric ward		23
Participant's work place		10

525 [a]The classification standard of educational level is according to China Statistical Yearbook 2014[34]

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526 . (7 Interview questions about the lived experience of women with GDM.

1. What are your experiences after you got to know that you had GDM?
2. What do you think about GDM?
3. Which physical changes have you experienced after you got GDM?
4. Which emotional changes have you experienced after you got GDM?
5. How did you manage your GDM?
6. How does GDM affect your life? (family and work)
7. What did you feel at the beginning when you got GDM?
8. What did you feel during the time living with GDM?

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528 . 47 Meaning unit, condensations, sub-themes included in the first theme (Being stricken by GDM).

Meaning unit	Condensation	Sub-theme
I felt that it was a shock when I knew I got GDM because GDM is a disease. I never never thought I would get the disease…. I couldn't accept it in my heart at the beginning. (Participant 55)	Shock	Experiencing different emotional reactions
At that moment when I was suddenly informed diabetes… May be… I thought that this was a kind of deviation from the blood test…an error. (Participant 8)	Doubt the diagnosis of GDM	
I felt very strange at that moment because I didn't have the concept (of GDM) and didn't know what GDM was. My husband also felt very strange. He said, 'Hey, how is pregnancy going with diabetes?' He felt very strange. (Participant 9)	Feel surprised and strange	
I hoped in my heart that I didn't get GDM. I would rather to believe other people's words such as 'You didn't get', 'Doesn't matter'… If I denied it, I would feel relieved. (Participant 49)	Deny	
I feared in my heart. Whether GDM would influence my baby if I couldn't control well?! Whether GDM would influence me?! I almost cried at that time. How could I get GDM? My family doesn't have the problem. Why I suddenly got it?!…I was scared. (Participant 30)	Fear	
When I saw the value was over the normal range, I thought, 'Bad! How do I get GDM?' I had seen the flyers of GDM. GDM may cause some symptoms such as premature birth. I was worried about it. I also heard about the pills and treatments if diabetes was severe. I did be worried about it. (Participant 7)	Worry	
People always say that it is good to eat fruits, so I ate a big volume of fruits every day. I ate five–six kinds of fruits per day. …Moreover, I very like to eat sweet potatoes. Maybe they are the factors that made me get GDM. (Participant 18)	Reflect the reasons of getting GDM	

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529 . 57 Meaning unit, condensations, sub-themes included in the second theme (Wishing to receive caring GDM care).

Meaning unit	Condensation	Sub-theme
I consulted doctor…. (Participant 25)	Seek help from health professionals	Seeking help
I consulted some friends who work in hospital... I searched on the internet…. I was a little nervous, so I called my mother. (Participant 25)	Seek help from the popular sector	
When I don't want to insist on (GDM regime), I will visit my doctor. I often go to do antenatal care. My doctor will encourage me, "Why did you not test? How can you eat the milk tea? (The milk tea contains much sugar)" I often talk with her. I am encouraged by her. (Participant 45)	Perceive support from health professionals	Perceiving the importance of the support from health professionals and husbands
After my husband knew my illness, he pays more attention to diet. Sometimes I very want to have a taste on something such as ice cream or cake, but he doesn't let me eat… He pays more attention to my illness than me. He urges me to do exercise… At least, it shows that he cares about me. (Participant 16)	Perceive support from husbands	
The obstetric doctor just said 'Observation'. I asked 'How do I observe?' She just said 'Come and check OGTT again after a period'…. The doctor still said "Observation" after the second OGTT…. She at most said, 'Pay more attention to your life style, your diet,	Perceive insufficient care of GDM from health professionals	Perceiving lack of caring GDM care from professionals

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and your exercise.' I cannot feel they care about me. (Participant 4)	
It seems that the reference values of GDM are different at different hospitals. The volume of the glucose powder used for OGTT test is also different at different hospitals. …. But the normal range of the blood glucose was the same at the two hospitals. I thought that maybe something was wrong, so I searched it in internet. There were many different kinds of answers about it in internet. I could not understand. (Participant 60)	Perceive inconsistent information about GDM

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532 . 87 Meaning unit, condensations, sub-themes included in the second theme (Being left alone to struggle with GDM).

Meaning unit	Condensation	Sub-theme
I'm particularly afraid of getting diabetes in the future…. You may imagine that the disease is getting worse and worse, and in one day you could be like the very sick person that you'd seen. (Participant 7)	Have been worrying about or afraid of the negative effects of GDM	Believing GDM should be treated seriously, but feel distressed
I have been seriously controlling my blood glucose, actually it is because I fear…I fear that I would really get diabetes when I was old. I do fear my baby isn't healthy…I adjusted my diet … I did the regular monitoring of blood glucose….I particularly wanted to control GDM well. (Participant 7)	Strive to control GDM	
I feel very distressed about diet control. I am easy to be hungry. Even though I am hungry, I cannot eat…I can't see other people eating, so I have to go away if I see it. But I will still think about the food after I go away, and then come back to have a look…I feel sad sometimes. (Participant 7)	Feel distressed	
I asked the doctor if I needed to test my blood glucose again when I did my next antenatal care. She said that it didn't matter, and let us see in the next month. After one month, I forgot to ask for checking my blood glucose when I came, she also forgot it. (Participant 21)	Be affected by the view of 'GDM not mattering' from professionals and people around them	Believing GDM is not a severe illness, but feel helplessness
My mother and other family think that many people got GDM which is very common, and GDM doesn't matter…. They always expect that I eat more foods… They fear that my nutrition isn't enough because they feel that I don't eat this and that, and I have requirements on diet as well. They feel that I am too tense because I always very pay attention to many things during my pregnancy. (Participant 5)		

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I have controlled according to doctor's advice, but the value of my blood glucose isn't decreased…Doctor said the same thing every time. She said that you paid attention to your diet. …I try not to eat if I am not hungry. I only eat cucumber and tomato instead of fruit, because they contain little sugar. No way. I have tried my best to control it. (Participant 5)	Control GDM based on the received information, but feel helplessness	
When the doctor showed me the test report, she didn't tell me that I got diabetes. She only said that the value was a little high. So I didn't pay attention to it. (Participant 36)	Be affected by the neglectful attitude of health professionals and people around	Believing GDM is nothing to worry about, but be unawareness
My family thinks that GDM is nothing. Every day, they give me the fruit and said, "Eat! It doesn't matter."… (Participant 13)		
My sister-in-law got gestational diabetes when she was pregnant. She doesn't have diabetes after she gave birth. Her baby is also healthy. Actually, the influence of gestational diabetes isn't big. (Participant 13)	Be affected by seeing healthy babies whose mother had GDM	
My physical body doesn't have any change, so I don't take gestational diabetes as a severe problem.... I think that gestational diabetes isn't a disease at all. … I didn't visit doctor. (Participant 8)	Be affected by feeling no physical body symptoms	
I don't know what influence gestational diabetes will bring to me. (Participant 8)	Don't know the future influence of GDM	

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535 . 97 Meaning unit, condensations, sub-themes included in the second theme (Trying to adjust and adapt to life with GDM).

Meaning unit	Condensation	Sub-theme
Slowly and slowly … Everything seems to be OK, I enjoy my pregnant months. …I don't know why I was so nervous in the early pregnant period. …My baby is growing and growing, and my belly is also bigger and bigger. I will think how my baby looks like in the future. The bigger my belly is, the more happiness I have. I am becoming a mother. (Participant 5)	Enjoy being a mother	Gradually adapting to being a mother with GDM
I relax my emotion and keep a peaceful mood…. It will influence my sleep if I am upset, thus I won't sleep well. If I have a good emotion, I will be happy, and my body and mood will be in a good situation. It is certainly good to my health. (Participant 7)	Try to be happy for the health of baby and themselves	
I know much about the GDM knowledge now. I pay more attention to my diet. I do more exercise. I think that I will be easy to get diabetes in the future, so I will pay attention to my diet, and I won't be lazy and will do more exercise. (Participant 14)	Try to be in a healthy life style	Trying to keep balance in life
My mother in law thinks that a pregnant woman is easy to be hit by a ghost when she goes out in the evening…. I do not insist on going out for a walk in the evening… I do exercise at lunch time. Anyway, just follow her saying. I hope I can be filial to my parents in law, I try not to be against their ideas as much as possible on behaviour and talking, although I sometimes do not like their old fashion view. (Participant 4)	Avoid practical difficulties	
I think that GDM is an alarm for me. It tells me that I will be easy to get type 2 diabetes in the future.	Think GDM is an alarm	Continuously

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(Participant 28) I worried that my baby will get diabetes in the future, because I think that living with diabetes is really a very painful thing. It will restrict his freedom, for example, he cannot eat what he wants to eat. …Chinese people look at food as heaven…It affects life much…I also fear that I will get diabetes when I am old. (Participant 55) I feel that the doctor isn't professional. She doesn't pay attention to GDM...I know most of the knowledge about GDM from internet.... The dissmeniation and health education about GDM are not enough. Therefore, some severe consequences,such as a baby dying in stomach, happened. ... It is important to make society pay attention to GDM. (Participant 10)	for the future health Reflect on the effects of GDM on the future health Reflect on the health education about GDM	reflecting on GDM

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No Item	Guide questions/description	Check box
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	√ Page6 Line 128
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	√ Page1 Line4-5
3. Occupation	What was their occupation at the time of the study?	√ Page1 Line7-9
4. Gender	Was the researcher male or female?	√ Page6 Line129
5. Experience and training	What experience or training did the researcher have?	√ Page17 Line407
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	X
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	√ Page5 Line120-124
8. Interviewer characteristics	What characteristics were reported about the interviewer /facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	√ Page17 Line 402-409
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	√ Page3 Line101
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	√ Page5 Line118
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	√ Page6 Line128
12. Sample size	How many participants were in the study?	√ Page5 Line107
13. Non-participation	How many people refused to participate or dropped out? Reasons?	√ Page5 Line108
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	√ Page5 Line110
15. Presence of non-Participants	Was anyone else present besides the participants and researchers?	√ Page5 Line119
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	√ Page5 Line108
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	√ Page25 √ Page6 Line131
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	√ Page6 Line128 Page5 Line107

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Addendum

19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	√ Page6 Line130
20. Field notes	Were field notes made during and/or after the interview or focus group?	X
21. Duration	What was the duration of the interviews or focus group?	√ Page6 Line129
22. Data saturation	Was data saturation discussed?	X
23. Transcripts returned	Were transcripts returned to participants for comment and /or correction?	X
Domain 3: analysis and findingsz		
Data analysis		
24. Number of data coders	How many data coders coded the data?	√ Page7 Line166
25. Description of the coding tree	Did authors provide a description of the coding tree?	X
26. Derivation of themes	Were themes identified in advance or derived from the data?	√ Page6-7
27. Software	What software, if applicable, was used to manage the data?	X
28. Participant checking	Did participants provide feedback on the findings?	X
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	√ Page26 -32
30. Data and findings consistent	Was there consistency between the data presented and the findings?	√ Page7 -13
31. Clarity of major themes	Were major themes clearly presented in the findings?	√ Page7 Line170
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	√ Page13-16

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Lived experience of women with gestational diabetes mellitus living in China: A qualitative interview study

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Key Words: Gestational diabetes; Qualitative Research; Life experiences; China

Word count: 4460

ABSTRACT

Objectives: To explore the lived experience of women with gestational diabetes mellitus (GDM) living in China in order to add knowledge about how the Chinese women suffer from GDM.

Design: A qualitative interpretive interview study. Data was collected with a snowball sampling technique. Phenomenological hermeneutics was used as the analysis method based on Ricoeur's phenomenological hermeneutical interpretation theory.

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Setting: The study was performed at the participants' work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China.

Participants: Inclusion criteria were: age ≥ 18 years, diagnosis of gestational diabetes mellitus without other pregnancy complications, in 34th gestational weeks – postpartum 4th weeks, and speaking Mandarin Chinese without speech impediment. 62 women, who met the inclusion criteria, took part in the study.

Results: The lived experience of the women with GDM living in China was formulated into a main theme: 'Longing for caring care'. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring care of GDM; Being left alone to struggle with GDM; and Trying to adjust and adapt to life with GDM.

Conclusion: The eagerness for caring care in China was highlighted. The lack of caring care could be one of the possible reasons why the professional-patient relations were deteriorating in China. It could be useful for health providers and health policymakers to receive education and training about caring care. Using the health metaphor of balance and 'patient participation' and 'patient-centred' approaches may benefit women with GDM and thus improve the quality of care in China.

Strengths and limitations of this study

- To our knowledge, this is the first study to explore the lived experience of women with GDM living in China.
- The large number of participants (N=62) presented the trustworthiness of the qualitative study.
- By using phenomenological hermeneutics a greater understanding of the essential meaning of living with GDM in China could be attained.
- We could not free ourselves from our pre-understanding which could produce bias.

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- Nuances could be lost in the translation process of the interview texts, which could influence the results of the study.

Introduction

Diabetes is a major health problem in China where the highest number of deaths in the world due to the illness has been recorded [1]. One of the types of diabetes, gestational diabetes mellitus (GDM) is associated with type 2 diabetes mellitus (T2DM); women who have been previously diagnosed with GDM will run a greater risk of developing T2DM later in life and GDM in subsequent pregnancies [2]. GDM plays a crucial role in the increasing prevalence of diabetes and obesity [3]. Uncontrolled GDM is also associated with serious complications for women with the illness and their foetus, for instance, obstructed labour and congenital abnormalities [3]. According to a study in 2015 in Tianjin of China, the prevalence of GDM in China is 8.1% by using the WHO criteria [4]. GDM is becoming a priority issue in public health of China. A recent study conducted in China reported that women living with GDM perceived a lack of high-quality GDM care.[5] According to Lindseth and Norberg [6], in order to be able to understand and improve healthcare practice, we have to start with the lived experience and express it in order to become aware of its meaning. This awareness itself often leads to improvements in the healthcare field.

The experiences of women with GDM in some socio-cultural contexts have been reported. In a metasynthesis study including studies from different countries worldwide, women with the illness experienced several negative feelings, such as fear and a loss of normality and personal control,[7] as well as in another study performed in Australia they reported uncertainty and scepticism.[8] Another review study[9] not only revealed women's negative feelings and thoughts, but also explored the women's struggle to manage GDM and their

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identity changes from a healthy person to being someone with GDM; their adaption to the changes; their concern for the health of their babies as well as their own health; their perception of seriousness of GDM and fear of T2DM. Furthermore, the experiences of Caucasian and South Asian women with GDM living in Canada illustrated a disconnection between diabetes prevention recommendations and the women's cultural practices.[10] However, to our knowledge, little was known about the lived experience of women with GDM living in China.

Studies conducted in China showed that the beliefs and health-related behaviour among women with GDM living in China were influenced by Chinese social culture.[11,12] A review study revealed that the influencing factors of the experience of women living with GDM included cultural roles and beliefs, social stigmas, social and professional support, and social roles and barriers to self-care.[9] In China, the social context is that the scale, frequency, and viciousness of violence against health professionals have shocked the world.[13] The increasing medical disputes including widely reported violent attacks, murders and protests in hospitals showed the deteriorating relationship between health professionals and patients.[14] However, GDM seriously depends on good professional-patient relations in order to obtain satisfied effects of health education due to the strict routine and lifestyle management that women with GDM have to perform.[15] Therefore, exploring the lived experience of women with GDM living in China would add knowledge of what it is like to live with GDM and how suffer it is for Chinese women. The study thus aimed to explore the lived experience of women with GDM living in China.

Methods

Design

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A qualitative interview study was conducted among women with GDM living in China by using phenomenological hermeneutics[6] inspired by Paul Ricoeur. [16]

Participants and setting

The inclusion criteria of participants were age ≥ 18 years, diagnosis of GDM without other pregnancy complications,[17] in the 34th gestational week – the postpartum 4th week, and speaking Mandarin Chinese without speech impediment. 62 women who met the inclusion criteria took part in the study (Table 1). The median age was 31 years (range 23 - 37). Four women refused to participate in the study, whose reasons were "I don't have time" or "I have to go back home now". The study was performed at the participants' work places, or at the obstetric clinic or ward at two provincial hospitals and one municipal hospital in the south east of China. A single room was chosen for each interview, which was most convenient for the participants. The study was approved by a university ethical board (No. 2012-033), and all conducted procedures conformed to the principles of Declaration of Helsinki.

---INSERT TABLE1 HERE---

Interviews and analysis

Participants were recruited by using a snowball sampling technique.[18] Women with GDM were referred to the interviewee of the study by participants or by four midwives who worked at hospital, and were then orally invited to participate in the study. They were first informed of the aim and the procedures of the study, and were assured of the right to withdraw at any time without negative consequences. They were informed that all transcripts were anonymous, and the analysis of data and presentation of results were carried out in such

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a way that no individual could be identified. They took part in the study voluntarily and their written informed consent was obtained.

Open-ended questions about the lived experience of women with GDM, which were developed by the authors, were used for data collection (Table 2). Individual narrative interviews were conducted face to face during August and December of 2014 by the first author, a native female Chinese with bilingual skills. Each interview lasted between 30~50 minutes, and was recorded with a digital audio recorder, and then transcribed verbatim in Chinese and translated from Chinese to English by the first author. Three pilot interviews were conducted and then discussed among the authors，which were included in this study based on their quality.

---INSERT TABLE2 HERE---

Phenomenological hermeneutics[6] based on Ricoeur's phenomenological hermeneutical interpretation theory [16] was used as the analysis method in this study. The analysis process consisted of three phases: naïve reading, structural analysis, and comprehensive understanding. In the naïve reading, the transcribed interview texts were first merged into one text, and then read several times as open-minded as possible in order to obtain its meaning as a whole. The maintenance of a phenomenological attitude was important during the naïve reading in order to formulate a naïve understanding of the text in phenomenological language.

In structural analysis, the whole text was read and divided into meaning units. The meaning units were read through and reflected on based upon the background of the naïve understanding, and were then condensed and expressed in everyday words as concisely as possible. All the condensed meaning units were read through and reflected on regarding similarities and differences, and then were sorted, further condensed and abstracted to form sub-themes. The sub-themes were reflected on and formulated in such a way as to present what the text talked about, thus leading to the formulation of themes. Reflection about the

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themes was based on the naïve understanding, and these explored in terms of whether they validated or invalidated the naïve understanding. If the structural analysis invalidated the naïve understanding, the whole text would be read again and a new naïve understanding would be formulated and checked by a new structural analysis. The process was repeated until the naïve understanding was indeed validated through the structural analysis.

In the comprehensive understanding, the third analysis phase, the whole text was reread as open-minded as possible with the naïve understanding and the validated themes in mind. Imagination and pre-understanding were used during the process. Relevant literature that seemed appropriate for helping to revise, widen and deepen the understanding was discussed between authors based on the meaning of the lived experience. The literature that could mutually illustrate the interview text was chosen for interpreting the text. The text was kept as close as possible as a whole again and re-contextualized in the light of the literature, and a comprehensive understanding of the text, i.e. the main theme, was attained by focusing on the possibilities of living in the world that the interview text opened up. According to Ricoeur,[16] a text could probably be interpreted in different ways, but the interpretation should be understood dialectically related to each other, overlap and interact with each other. Dialectical interpretation of the text and the meaning of the lived experience were achieved by discussion between the three authors.

Findings

The lived experience of the women with GDM living in China was formulated into a main theme: ‘Longing for caring care’. The main theme was derived from four themes: Being stricken by GDM; Wishing to receive caring GDM care; Being left alone to struggle with GDM; Trying to adjust and adapt to life with GDM.

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Naïve analysis

The women in the study described their initial emotional reactions when they were informed of the diagnosis of GDM. They experienced shock, doubt, surprise, feeling strange, denial, fear, and worry. They reflected on the reasons of getting it and sought help from the health professionals and popular sectors, i.e. relatives, friends, internet and books. It appears that they did not initially receive the satisfactory answers about GDM from the health professionals, so they sought help from the popular sector. They perceived that the information obtained about GDM was inconsistent. After considering all the information, women were always afraid of and worried about having the illness; or women believed it was not a severe illness; or women thought that it was nothing to worry about. The women's experiences of GDM contained distressed feelings caused by the illness, helplessness, confusion and neglectful attitude from health professionals and people around.

Structural analysis

Four themes emerged during the structural analysis including being stricken by GDM, wishing to receive caring GDM care, being left alone to struggle with GDM, trying to adjust and adapt to life with GDM. These themes were described with sub-themes, condensation units, and meaning units.

Being stricken by GDM (Table 3)

After women in the study were informed of the diagnosis of GDM, they were stricken by emotional chaos. They were shocked and surprised, and felt strange at the beginning. Some of them could not accept the fact, and thus doubted and denied the diagnosis of GDM.

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Nevertheless, they were afraid of and worried about the negative effects of GDM on their babies and themselves. When the women experienced these emotional reactions, they also reflected on the reasons for getting the illness. They believed the reasons were eating too much fruits and sweets, obesity, and advanced maternal age.

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Wishing to receive caring GDM care (Table 4)

After the women saw the abnormal result of the OGTT, they began to seek help from different resources. A woman said, *"I consulted doctor and some friends who work in hospital... I searched on the internet…. I was a little nervous, so I called my mother".* However, they perceived that the information received about the illness was inconsistent. They thought that the support and encouragement from health professionals and their husbands were important and could promote their health behaviour. They, however, perceived that the GDM care from health professionals was insufficient and uncaring. They complained about the health education from the professionals being unclear and lacking detail because of the large number of patients waiting. Some thought that the doctors and midwives were not professional about GDM and did not take the illness seriously. They wished to receive caring GDM care.

The obstetric doctor just said 'Observation'. I asked 'How do I observe?' She just said 'Come and check OGTT again after a period'…. The doctor still said "Observation" after the second OGTT…. She at most said, 'Pay more attention to your life style, your diet, and your exercise.' I cannot feel they care about me. (Participant 5)

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Being left alone to struggle with GDM (Table 5)

The beliefs and experiences of the women in the study could be divided into three styles: they believed the illness should be treated seriously, but felt distress; or they believed it was not a severe illness, but at the same time experienced helplessness; or they believed it was nothing to worry about, and ignored the seriousness of having GDM. These personal beliefs and experiences showed that women in the study were left alone to struggle with GDM.

The women who believed GDM should be treated seriously thought that their health was their own, and they should take responsibility for attaining a normal value for their blood glucose level. They were worried about or afraid of the negative effects of GDM, and strove to seek information from health professionals and control GDM. A participant explained her fear of T2DM in the future, which is one of the risks for women with GDM, as well as her notion about the desperate feeling of getting the lifetime disease. "*I'm particularly afraid of getting diabetes in the future…. You may imagine that the disease is getting worse and worse, and in one day you could be like the very sick person that you'd seen."* Some women even systematically searched for GDM knowledge. They fully complied with the advice of health professionals and gave up their previous unhealthy lifestyle and their favourite food, which could increase their blood glucose. They attained the stable normal value of blood glucose, but they felt distressed because of being restricted from enjoying food, the special way other people looked at, and the pain caused by the needle pricks when self-monitoring blood glucose. A woman talked about their inner struggle about diet control, "*I can't see other people eating, so I have to go away if I see it. But I will still think about the food after I go away, and then come back to have a look…*"

The women who believed GDM was not a severe illness were affected by the views of "*GDM does not matter*" from the health professionals and people around them. In terms of

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behaviour, the women with the style of belief controlled GDM based on the information they received. Once the value of their blood glucose was normal, the women thought that they recovered from GDM and returned to their previous customary lifestyle. However, some women felt helpless because they wanted to keep the value of their blood glucose in the normal range but the blood glucose could not be controlled well.

I think gestational diabetes isn't a big illness, but I want to be healthy…I controlled according to doctor's advice…Doctor said the same thing every time. She said that you paid attention to your diet. …I try not to eat if I am not hungry. I only eat cucumber and tomato instead of fruit, because they contain little sugar. No way. I have tried my best to control it, but the values still aren't in the normal range. (Participant 40)

The women who believed GDM was nothing to worry about almost ignored GDM and did not know about the future risk of GDM. They thought that their GDM was nothing to worry about because the value of their blood glucose was only a little high; they had seen that the babies born by mothers with GDM were healthy; and their physical body did not have abnormal symptoms. Some women even thought that GDM was not a disease at all. The women thought that they were influenced by the ignoring attitude of health professionals and people around them. A participant described the talking situation with her doctor about GDM, "*When the doctor showed me the test report, she didn't tell me that I got gestational diabetes. She only said that the value was a little high. So I didn't pay attention to it.*" The women said that they asked different people after they were diagnosed with GDM. All the people around them said that there was nothing to worry about if the value of the blood glucose was just a little high; and the elderly always said that a big baby was good and very easy to bring up. In terms of behaviour, they almost did nothing related to GDM.

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Trying to adjust and adapt to life with GDM (Table 6)

The women in the study had been trying to adjust and adapt to their lives with GDM during their pregnancy. With their foetus growing, they adapted to being a mother with GDM and gradually began to enjoy the feeling of being a mother. They believed that their emotions would influence their baby's personality and the health of their babies and themselves. They and their baby would be in a good situation if they were in a good mood. They thus tried to be happy. They also sought a balance between trying to practice a healthy life style and avoiding practical difficulties. For example, they compromised with their parents' views on their life style because they wanted to show filial piety to their parents and parents-in-law by obeying the latter' views even if they did not like their parents' old fashioned views. Moreover, they continuously reflected on GDM. The women realized that the illness was like an alarm bell for their future health, and reflected a great deal on the effects of GDM on their future health and the current health education of it as well. They believed that people in general were not aware of what GDM was. They thought that the illness should be prevented at the beginning of a pregnancy and that the knowledge about GDM should be disseminated to everyone in society.

---INSERT TABLE6 HERE---

Comprehensive understanding

The women with GDM in the study seemed to be suffering due to their illness, treatment and lack of caring care. They complained about the neglectful attitude to GDM among health professionals, as well as a lack of health education about GDM and an understanding of GDM

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from the whole society. It seemed that they were eager to receive professional care and not be left alone to struggle with GDM. A study showed that good care from the patients' perspectives was patient-focused, individualized and involved care related to their needs; it was provided in a humanitarian way by the health providers who presented their involvement, commitment and concern to patients.[19] Martinsen points out that caring includes having consideration for, being concerned about, and taking care of the other.[20] According to Eriksson,[21] caring, as an ethos of love and compassion, implies alleviation of suffering in love, charity, faith, and hope, and serves life and health. Based on the literature, our comprehensive understanding of the women's narratives was formulated as 'Longing for caring care'.

Discussion

The Chinese women experienced being stricken by emotional chaos after they were diagnosed with GDM. When seeking care, they wished to receive caring GDM care. When they struggled with GDM, their beliefs and experiences showed that they were left alone. However, they tried to adjust and adapt to life with GDM. Their lived experience showed that they longed for caring care.

The women in the present study experienced emotional chaos such as doubt and fear. Similar emotional reactions were showed in a metasynthesis study about perceptions among women with GDM.[7] A study conducted in Canada showed that the strict regime such as diet control increased the women's anxiety and stress during pregnancy.[22] These studies illustrated that women's experiences of living with GDM could be overwhelming. Moreover, women who believed that GDM should be treated seriously strove to control the illness and attained a stable normal blood glucose level, which was similar to other study findings.[23]

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However, they felt distressed with the strict GDM regime. Some women felt unsupported by health professionals and their own close contacts/family on the GDM regime. They were left alone to face to the distress. A study has showed that the psychological aspect was pivotal in helping and encouraging women with GDM to promote self-management of the illness and better control of it.[24] It is suggested that health providers and the women's family members needed to have an understanding and care of the women's psychological wellbeing and on-going mental health.

Meanwhile, some women in the present study believed that GDM was not a severe illness or that GDM was nothing to worry about, but they felt helplessness or unawareness. One of the reasons for this was the women's perception of GDM: they did not perceive that they had any symptoms; they and their babies were "normal" after being checked in hospital; and they had seen other women with GDM and these women's neonates did not have any problems generated by GDM. A study showed that a lower level of risk awareness about GDM was related to limited knowledge about the body and GDM.[23] Another study showed that lower levels of health literacy and risk awareness of GDM might relate to a risk for poorer self-management of GDM.[25] The present study showed that these women's poorer self-management of GDM related to a lack of necessary knowledge about GDM. For example, one of their misunderstandings on diet control was that they returned to their previous diet once the value of their blood glucose was normal. Another aspect of the reasons for having the beliefs was due to the influence of the neglectful attitude to GDM of health professionals and people around. The women in the study complained that they lacked sufficient health education about GDM. They were left alone by health professionals and people around them. According to Helman,[26] people suffering from physical discomfort or emotional stress seek help from professional, popular and folk sectors, and thus form their own beliefs and behaviour. They construct their reality of health and illness in aspects of biological and mental

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patterns, characteristics of their image of body, mind, and soul, ethnicity and family structures of community and society, and experiences of care. The present study showed that women's beliefs were influenced by health professionals and people around them. Orem stated that nursing systems are action systems formed by health providers through the practice of their nursing agency for persons with health-derived or health-associated limitations in self-care or dependent care.[27] The nursing systems may be produced for individuals, for persons who constitute a dependent-care unit, and for families and other multiperson units. Therefore, in order to support the women and promote the women's health-related behaviour in the healthcare system, the neglectful attitude to GDM of some of health providers ought to be changed; health education about GDM should involve women with GDM, their family members, communities, and society.

Moreover, women in the present study tried to adjust and adapt to life with GDM. They adapted gradually to being a mother with GDM, tried to keep a balance in life, and reflected continuously on GDM. A study in a group of Cambodian women showed that the core perception of health was "seeking life balance".[28] Physical, emotional, spiritual, psychological, and social considerations play different roles in the need for balance. According to Roy,[29] health is a reflection of adaptation, i.e. the interaction of the person and the environment aimed to be a state and a process of being and becoming integrated and a whole human being. In the present study, women presented the process of adjusting and adapting to life with GDM to attain the physiological, psychological, and social integrity. Using the health metaphor concerning balance may thus be better for the health education of women with GDM than the more conventional methods of control and restriction. Making health providers understand patients' needs and thus help patients to reach a life balance, using 'patient participation' and 'patient-centred' approaches may benefit the women with GDM.

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Based on the lived experience, the women in the present study seemed to be suffering due to their illness, treatment and lack of caring care. The feeling of caring is generated by the resonance between patients and caregivers, and the acknowledgement of the individual with respect from a person-centred perspective.[30] A study showed that good care from the patients' perspectives were patient-focused, individualized and involved care related to their needs; nor, conversely, care was described as 'Not so good', which was given in an impersonal manner, routine-based, unrelated to needs, and by staff who were distant and did not know or were not involved with the patients.[19] According to Eriksson,[21] patients' experiences of suffering related to care are: not to be taken seriously, not to be welcome, being blamed, and being subjected to exercise of power. The present study presented the suffering related to care and reflected on women's eagerness to caring care. The lack of caring care in the study could be a possible explanation why the professional-patient relations are declining in China. It is thus necessary, in professional context, to strengthen caring care for women with GDM in China. Caring, however, requires education and training[20] and thus in order to update and perform the diabetes guidelines and routines with a humanistic care approach, it would be beneficial if health providers and health policymakers received education and training about caring care.

Strengths and limitations

To our knowledge, this is the first study to explore the lived experience of women with GDM living in China. However, the essence of people's lived experiences is what is invariable in all the variations of the phenomenon and is not easily expressed by people.[31] By using phenomenological hermeneutics[6] a greater understanding of the essential meaning of living with GDM in China can be attained, which is possible to make stakeholders related to an illness understand each other better and thus improve healthcare practice. The ordinary

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world of women living with GDM could thus be transcended in the search of the true knowledge by the evidence of their lived experiences.[31] Moreover, the large number of participants (N=62) also presented the trustworthiness of the qualitative study.

However, we cannot be free ourselves from our pre-understanding, which could produce bias.[32] Through critical reflection, discussion between authors and using relevant literature, we revised, broadened and deepened our awareness, and reduced the bias from our pre-understanding. Meanwhile, losing nuances in the translation process of the interview texts could be another limitation of the study.[33] In order to reduce the translation problems, the first author, who had bilingual skills and have accepted the training of qualitative research methodology, transcribed the interviews verbatim in Chinese and translated the texts into English.

Conclusions

The eagerness for caring care in China was highlighted in the study. The lack of caring care could be one of the possible reasons why the professional-patient relations in China were deteriorating. The results of this study could be used as a contribution to strengthen caring care in China by carrying out and updating diabetes guidelines and routines with aspects of humanistic and psychological care, and training health providers in caring care. Using the health metaphor concerning balance and 'patient participation' and 'patient-centred' approaches may benefit the women with GDM and thus improve the quality of GDM care.

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Contributors Study design was by LG, KW and MR; data collection was by LG; data analysis was by LG, KW and MR; manuscript preparation was by LG, KW and MR; and final approval of the version to be submitted was by LG, KW and MR.

Conflict of interest None declared.

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Table 1 Characteristics of the interviewed Chinese women with GDM (n=62)

Variable	Median (range)	Number
Age (year)	31 (23-37)	62
34th gestational week – before birth		39
Postpartum 1st week – postpartum 4th week		23
Relapse in GDM		5
GDM symptoms such as thirst and ketoacidosis		9
Present treatment for GDM		
No treatment		3
Diet		22
Diet+exercise		29
Diet+Insulin		8
Current nutritional supplements such as multivitamin and minerals		55
Nulliparous		44
Parous		18
Educational level[a] (duration)		
Senior Secondary Education (12-13 years)		30
Higher Education (≥ 15 years)		32
Present working condition		
Employed		30
Unemployed		25
Sick-leave		7
Family circumstances		
Married		61
Interview setting		
Obstetric clinic		29
Obstetric ward		23
Participant's work place		10

[a]The classification standard of educational level is according to China Statistical Yearbook 2014[34]

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Table 2. Interview questions about the lived experience of women with GDM.

1. What are your experiences after you got to know that you had GDM?
2. What do you think about GDM?
3. Which physical changes have you experienced after you got GDM?
4. Which emotional changes have you experienced after you got GDM?
5. How did you manage your GDM?
6. How does GDM affect your life? (family and work)
7. What did you feel at the beginning when you got GDM?
8. What did you feel during the time living with GDM?

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525 **Table 3.** Meaning unit, condensations, sub-themes included in the first theme (Being stricken by GDM).

Meaning unit	Condensation	Sub-theme
I felt that it was a shock when I knew I got GDM because GDM is a disease. I never never thought I would get the disease…. I couldn't accept it in my heart at the beginning. (Participant 55)	Shock	Experiencing different emotional reactions
At that moment when I was suddenly informed diabetes… May be… I thought that this was a kind of deviation from the blood test…an error. (Participant 8)	Doubt the diagnosis of GDM	
I felt very strange at that moment because I didn't have the concept (of GDM) and didn't know what GDM was. My husband also felt very strange. He said, 'Hey, how is pregnancy going with diabetes?' He felt very strange. (Participant 9)	Feel surprised and strange	
I hoped in my heart that I didn't get GDM. I would rather to believe other people's words such as 'You didn't get', 'Doesn't matter'… If I denied it, I would feel relieved. (Participant 49)	Deny	
I feared in my heart. Whether GDM would influence my baby if I couldn't control well?! Whether GDM would influence me?! I almost cried at that time. How could I get GDM? My family doesn't have the problem. Why I suddenly got it?!…I was scared. (Participant 30)	Fear	
When I saw the value was over the normal range, I thought, 'Bad! How do I get GDM?' I had seen the flyers of GDM. GDM may cause some symptoms such as premature birth. I was worried about it. I also heard about the pills and treatments if diabetes was severe. I did be worried about it. (Participant 7)	Worry	
People always say that it is good to eat fruits, so I ate a big volume of fruits every day. I ate five–six kinds of fruits per day. …Moreover, I very like to eat sweet potatoes. Maybe they are the factors that made me get GDM. (Participant 18)	Reflect the reasons of getting GDM	

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526 **Table 4.** Meaning unit, condensations, sub-themes included in the second theme (Wishing to receive caring GDM care).

Meaning unit	Condensation	Sub-theme
I consulted doctor…. (Participant 25)	Seek help from health professionals	Seeking help
I consulted some friends who work in hospital... I searched on the internet…. I was a little nervous, so I called my mother. (Participant 25)	Seek help from the popular sector	
When I don't want to insist on (GDM regime), I will visit my doctor. I often go to do antenatal care. My doctor will encourage me, "Why did you not test? How can you eat the milk tea? (The milk tea contains much sugar)" I often talk with her. I am encouraged by her. (Participant 45)	Perceive support from health professionals	Perceiving the importance of the support from health professionals and husbands
After my husband knew my illness, he pays more attention to diet. Sometimes I very want to have a taste on something such as ice cream or cake, but he doesn't let me eat… He pays more attention to my illness than me. He urges me to do exercise… At least, it shows that he cares about me. (Participant 16)	Perceive support from husbands	
The obstetric doctor just said 'Observation'. I asked 'How do I observe?' She just said 'Come and check OGTT again after a period'…. The doctor still said "Observation" after the second OGTT…. She at most said, 'Pay more attention to your life style, your diet,	Perceive insufficient care of GDM from health professionals	Perceiving lack of caring GDM care from professionals

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and your exercise.' I cannot feel they care about me. (Participant 4)		
It seems that the reference values of GDM are different at different hospitals. The volume of the glucose powder used for OGTT test is also different at different hospitals. …. But the normal range of the blood glucose was the same at the two hospitals. I thought that maybe something was wrong, so I searched it in internet. There were many different kinds of answers about it in internet. I could not understand. (Participant 60)	Perceive inconsistent information about GDM	

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Table 5. Meaning unit, condensations, sub-themes included in the second theme (Being left alone to struggle with GDM).

Meaning unit	Condensation	Sub-theme
I'm particularly afraid of getting diabetes in the future…. You may imagine that the disease is getting worse and worse, and in one day you could be like the very sick person that you'd seen. (Participant 7)	Have been worrying about or afraid of the negative effects of GDM	Believing GDM should be treated seriously, but feeling distressed
I have been seriously controlling my blood glucose, actually it is because I fear…I fear that I would really get diabetes when I was old. I do fear my baby isn't healthy…I adjusted my diet … I did the regular monitoring of blood glucose….I particularly wanted to control GDM well. (Participant 7)	Strive to control GDM	
I feel very distressed about diet control. I am easy to be hungry. Even though I am hungry, I cannot eat…I can't see other people eating, so I have to go away if I see it. But I will still think about the food after I go away, and then come back to have a look…I feel sad sometimes. (Participant 7)	Feel distressed	
I asked the doctor if I needed to test my blood glucose again when I did my next antenatal care. She said that it didn't matter, and let us see in the next month. After one month, I forgot to ask for checking my blood glucose when I came, she also forgot it. (Participant 21)	Be affected by the view of 'GDM not mattering' from professionals and people around them	Believing GDM is not a severe illness, but at the same time experiencing helplessness
My mother and other family think that many people got GDM which is very common, and GDM doesn't matter…. They always expect that I eat more foods… They fear that my nutrition isn't enough because they feel that I don't eat this and that, and I have requirements on diet as well. They feel that I am too tense because I always very pay attention to many things during my pregnancy. (Participant 5)		

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I think gestational diabetes isn't a big illness, but I want to be healthy…I controlled according to doctor's advice…Doctor said the same thing every time. She said that you paid attention to your diet. …I try not to eat if I am not hungry. I only eat cucumber and tomato instead of fruit, because they contain little sugar. No way. I have tried my best to control it, but the values still aren't in the normal range. (Participant 40)	Control GDM based on the received information, but feel helplessness	
When the doctor showed me the test report, she didn't tell me that I got diabetes. She only said that the value was a little high. So I didn't pay attention to it. (Participant 36)	Be affected by the neglectful attitude of health professionals and people around	Believing GDM is nothing to worry about, and ignoring the seriousness of having GDM
My family thinks that GDM is nothing. Every day, they give me the fruit and said, "Eat! It doesn't matter."… (Participant 13)		
My sister-in-law got gestational diabetes when she was pregnant. She doesn't have diabetes after she gave birth. Her baby is also healthy. Actually, the influence of gestational diabetes isn't big. (Participant 13)	Be affected by seeing healthy babies whose mother had GDM	
My physical body doesn't have any change, so I don't take gestational diabetes as a severe problem.... I think that gestational diabetes isn't a disease at all. … I didn't visit doctor. (Participant 8)	Be affected by feeling no physical body symptoms	
I don't know what influence gestational diabetes will bring to me. (Participant 8)	Don't know the future influence of GDM	

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Table 6. Meaning unit, condensations, sub-themes included in the second theme (Trying to adjust and adapt to life with GDM).

Meaning unit	Condensation	Sub-theme
Slowly and slowly … Everything seems to be OK, I enjoy my pregnant months. …I don't know why I was so nervous in the early pregnant period. …My baby is growing and growing, and my belly is also bigger and bigger. I will think how my baby looks like in the future. The bigger my belly is, the more happiness I have. I am becoming a mother. (Participant 5)	Enjoy being a mother	Gradually adapting to being a mother with GDM
I relax my emotion and keep a peaceful mood…. It will influence my sleep if I am upset, thus I won't sleep well. If I have a good emotion, I will be happy, and my body and mood will be in a good situation. It is certainly good to my health. (Participant 7)	Try to be happy for the health of baby and themselves	
I know much about the GDM knowledge now. I pay more attention to my diet. I do more exercise. I think that I will be easy to get diabetes in the future, so I will pay attention to my diet, and I won't be lazy and will do more exercise. (Participant 14)	Try to be in a healthy life style	Trying to keep balance in life
My mother in law thinks that a pregnant woman is easy to be hit by a ghost when she goes out in the evening…. I do not insist on going out for a walk in the evening… I do exercise at lunch time. Anyway, just follow her saying. I hope I can be filial to my parents in law, I try not to be against their ideas as much as possible on behaviour and talking, although I sometimes do not like their old fashion view. (Participant 4)	Avoid practical difficulties	
I think that GDM is an alarm for me. It tells me that I will be easy to get type 2 diabetes in the future.	Think GDM is an alarm	Continuously

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(Participant 28)	for the future health	reflecting on GDM
I worried that my baby will get diabetes in the future, because I think that living with diabetes is really a very painful thing. It will restrict his freedom, for example, he cannot eat what he wants to eat. …Chinese people look at food as heaven…It affects life much…I also fear that I will get diabetes when I am old. (Participant 55)	Reflect on the effects of GDM on the future health	
I feel that the doctor isn't professional. She doesn't pay attention to GDM...I know most of the knowledge about GDM from internet.... The dissmeniation and health education about GDM are not enough. Therefore, some severe consequences,such as a baby dying in stomach, happened. ... It is important to make society pay attention to GDM. (Participant 10)	Reflect on the health education about GDM	

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No Item	Guide questions/description	Check box
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	√ Page6 Line 128
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	√ Page1 Line4-5
3. Occupation	What was their occupation at the time of the study?	√ Page1 Line7-9
4. Gender	Was the researcher male or female?	√ Page6 Line129
5. Experience and training	What experience or training did the researcher have?	√ Page17 Line407
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	X
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	√ Page5 Line120-124
8. Interviewer characteristics	What characteristics were reported about the interviewer /facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	√ Page17 Line 402-409
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	√ Page3 Line101
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	√ Page5 Line118
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	√ Page6 Line128
12. Sample size	How many participants were in the study?	√ Page5 Line107
13. Non-participation	How many people refused to participate or dropped out? Reasons?	√ Page5 Line108
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	√ Page5 Line110
15. Presence of non-Participants	Was anyone else present besides the participants and researchers?	√ Page5 Line119
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	√ Page5 Line108
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	√ Page25 √ Page6 Line131
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	√ Page6 Line128 Page5 Line107

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Addendum

19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	√ Page6 Line130
20. Field notes	Were field notes made during and/or after the interview or focus group?	X
21. Duration	What was the duration of the interviews or focus group?	√ Page6 Line129
22. Data saturation	Was data saturation discussed?	X
23. Transcripts returned	Were transcripts returned to participants for comment and /or correction?	X
Domain 3: analysis and findingsz		
Data analysis		
24. Number of data coders	How many data coders coded the data?	√ Page7 Line166
25. Description of the coding tree	Did authors provide a description of the coding tree?	X
26. Derivation of themes	Were themes identified in advance or derived from the data?	√ Page6-7
27. Software	What software, if applicable, was used to manage the data?	X
28. Participant checking	Did participants provide feedback on the findings?	X
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	√ Page26 -32
30. Data and findings consistent	Was there consistency between the data presented and the findings?	√ Page7 -13
31. Clarity of major themes	Were major themes clearly presented in the findings?	√ Page7 Line170
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	√ Page13-16

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